# Supporting families in the context of adult traumatic brain injury

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**Title:** Supporting Families in the Context of Adult Traumatic Brain Injury

**Abstract:** Families are fundamental to the wellbeing, quality of life and functional and social outcomes of individuals who sustain traumatic brain injury (TBI). However, the family is often vulnerable and at risk from the challenge of supporting an individual who has been left with long-term neurological disability. Considering the young population often affected, the resulting conditions can have significant emotional and financial burden for families and service providing for their long-term needs. The National Service Framework for Long-term Conditions acknowledges that the whole family is affected by neurological disability and it suggests that a 'whole-family' approach to managing TBI may be useful. This paper will argue that both family systems theory and family-centred care are frameworks that may be helpful in achieving the 'whole-family' approach in practice. However, future research is needed that will assess the efficacy of these and other approaches so that health-care services know the true value of any such intervention.

**Key Points**

- A whole-family approach is required to manage long-term neurological disability.
- A supportive and well functioning family is an important component of positive experiences following TBI
- Understanding the family system may help care providers to plan individual and effective care

- If carefully implemented Family Centred Care may provide a framework to assist practitioners to work with the whole family
- Future research is needed to evaluate interventions that are used to manage TBI in the context of the whole family

**Key Words**

- Traumatic Brain Injury
- Whole-family approach
- Family Centred Care
- Family Systems

**Introduction**

Families are fundamental to the wellbeing, quality of life and functional/social outcomes of individuals who sustain Traumatic Brain Injury (TBI) (Turner-Stokes, 2003). However, the family is often vulnerable and at risk from the challenge of supporting an individual who has been left with long-term neurological disability. Within the literature Jumisko et al (2007) believes there is a general lack of understanding about the challenges faced by families affected by TBI. This lack of knowledge may account for why health services appear limited in their capacity to effectively help them (Ellis-Hill, 2001). A 'whole-family approach' to managing TBI is a new innovation led by the National Service Framework for Long-term Conditions (NSF-LTC) (DoH, 2005), but there needs to be greater clarity about what this approach is and how it can be supported in practice. This paper aims to bring together the evidence base in relation to this whole-family approach and its application in practice. Both Family Systems Theory and Family Centred Care (FCC) will

be explored as possible frameworks to achieve a whole-family approach. The implications of FCC will be discussed and recommendations will then be made for how the evidence base may be developed in the future.

**Brain Injury**

An injury to the brain occurring after birth is classified as an Acquired Brain Injury (ABI) (Cree, 2003). ABIs are characteristically sudden onset conditions that are followed by varying degrees of recovery (DoH, 2005). Non traumatic injuries are caused by strokes or infections and are therefore different from traumatic injuries that may be caused by falls, assaults or road traffic accidents (Hickey, 2003). Hospital episode statistics for 2005-2006 show head injuries to account for approximately 150,000 admissions per year to NHS hospitals in England (HESonline, 2007). Those who sustain head injuries are predominantly men, some figures suggest a 2:1 ratio of male to female (HESonline, 2007) and others approximately 3:1 or higher (Powell, 2004). Age is also known to be associated with a higher risk of head injury with a large number sustained in the younger population (approximately 16-25) (Sorenson and Kraus, 1991). This association has been attributed to people in younger age groups engaging in high risk behaviours (Powell, 2004). TBI therefore, poses a major challenge for health care services (Engberg and Teasdale, 2004).

Many of those who recover from a TBI never return to their previous life and will have some change to their previous level of functioning. Wood et al (2005) suggest that diverse and complex physical or cognitive changes are a “frequent legacy” of brain injury (p845). These changes can require small adjustments in daily routines or complete dependency on others for every activity of daily living. Sequelae range from deficits in motor and physical ability, psychosocial and emotional challenges (Donnelly, et al 2005) to memory loss and attention

difficulties (Wood et al, 2005; Engberg and Teasdale 2004). Considering the young population often affected, the resulting conditions can have significant emotional and financial burden for families and service providing for their long term needs (Gottesman, et al 2003). Furthermore, life expectancy is usually only minimally reduced, therefore the individual and the family will have to live with the consequences for many years.

**The importance of family**

The importance of a supportive and well functioning family often emerges as a key finding regarding the experience of living with, caring for or being affected by another person's TBI (Hanks et al, 2007; Jumisko et al, 2007; Yeates et al, 2007; Wells et al 2005). Wells et al (2005) surveyed 72 family members who identified themselves as the primary carer. Although caring was generally regarded more positively than negatively it was the family as a support mechanism that featured as a significant moderator of negative feelings about caregiving and also for feelings of anxiety and depression. In a study of 60 primary caregivers Hanks et al (2007) also found the family to be important. Hanks et al observed a strong relationship between both effective family functioning and social support with appraisals of caregiver burden, relationship status and sense of caregiving mastery. The experiences of 170 siblings were investigated by Degeneffe and Lynch (2006) who identified a significant relationship between the perceived lack of social support and increased levels of depression. Within the qualitative literature Wongvatunyu and Porter (2005) interviewed 7 mothers of young adults with TBI. Their results showed that support from the rest of the family can act as a moderator of depressive symptomology such as anxiety, stress and sleep disturbances.

A supportive and well functioning family system is therefore a crucial component of positive experiences following TBI for both injured and non-injured members. However Duff (2006) identifies that much of the relevant literature in this field uses a cross-sectional design to investigate family outcomes and thus these are limited to only a snapshot of the experience. Duff suggests that research has not yet established how the family evolves over time, and has only just started to explore the complexity of family contexts, family capacity, resilience, and the process of family adaptation.

**Policy**

In March 2005 the NSF-LTC was launched. The NSF focuses on neurological conditions, although it can be applied to anyone with a long-term condition (DoH, 2005). Within the NSF Quality Recommendation 10 (QR10) outlines the government's strategy to support families and carers. Although QR10 initially identifies the need to support carers both in their role as a carer and also in their own right, it goes on to acknowledge that the whole family is affected by this injury. It then suggests that a 'whole-family approach' to managing TBI may be helpful (DoH, 2005, p.55). In contrast to previous policy (DoH, 2000; 1999) and statutory acts of law (Carers Act, 2004; 1995), which imply there is a carer and a cared for, the NSF-LTC recognises that TBI, and other long-term conditions, affect more than just the identified primary carer. Therefore it would seem reasonable for services to reflect this and address the support needs of the whole family.

More recently Lord Darzi's review of the NHS set out an agenda for the future of health and health care (Darzi, 2008). The review included long-term conditions as a priority and advocated that all those with a long-term condition should have a personalised care plan. The care plan would organise services around the service user's individual needs. This personalised care was

previously outlined in the white paper 'Our Health, Our Care Our Say' (DoH, 2006) however Lord Darzi's review suggests that in the next two years, all of the 15 million people with long-term conditions should be offered a personalised care plan. These plans are dependant on partnership working between service users and the professionals who deliver those services. The review goes on to state that:

*"Personal care also considers the needs of the patient within the context of their support network, including carers, family and employers"*
(DH, 2008, p.21)

This statement identifies the need to consider the family context of the person whose health care needs are of primary concern. Understanding family dynamics is therefore an important consideration in planning care. Working more closely with families may therefore help to achieve more effective and individualised care. Planning care in this way may improve not only the life of the injured family member but also the lives of the rest of the family who are affected by this injury.

**Working with families**

Defining the family is traditionally problematic and definitions are often restrictive. The difficulty of defining the family may, therefore, be one reason why working with the family is challenging. The family structure may be nuclear or extended, traditional or contemporary and it is difficult to apply one single definition (Broderick, 1993). However Shields et al (2007) developed Nixon's 1988 definition of family to include significant others who do not usually cohabit with the family. Further to this, the definition also allows those in non-traditional family roles, i.e. guardians, to

be considered as an integral part of the family structure. This inclusive definition may therefore be useful to healthcare practice:

*"The family is a basic social unit having at its nucleus two or more persons, irrespective of age, in which each of the following conditions are present:*
*a) the members are related by blood, or marriage, or adoption, or by a contract which is either explicit or implied;*
*b) the members communicate with each other in terms of defined social roles such as mother, father, wife, husband, daughter, son, brother, sister, grandfather, uncle, aunt; and*
*c) they adopt or create and maintain common customs and traditions."*
(Nixon 1988 cited in Shields et al, 2007, p.6)

One of the strengths of this definition is that it makes clear that families have unique ways of existing together. One approach to improve collaboration with families is to explore and understand these unique dynamics and the wider family context. A family systems approach may be helpful in achieving this and improving family support (Yeates et al, 2007; Gan et al, 2006; Curtiss et al, 2000; Kosciulek and Lustig, 1999; Kosciulek, 1996)
It is also possible that Family Centred Care could provide a practical framework for brain injury services to achieve the whole-family approach advocated by the NSF.

*Family Systems (Subheading)*
Family systems theory views the family as containing a structure, rules of operating and established methods of communicating (Maitz and Sachs, 1995). Family systems theory also illustrates how one part of the family cannot be understood in isolation from others. This

enables examination of how changes in one member cause changes to occur in other family members and how the system as a whole then responds to this change (Walker & Akister, 2004, Maitz and Sachs, 1995, see Box 1). Although a conceptual framework the model adopted by Turnball & Turnball (1991) in the publication 'Head Injury a Family Matter' may be helpful to understand the family within the context of TBI (Figure 1). This model places family members at the centre and starting from this point family characteristics, the family life cycle and family functions are considered (Turnball & Turnball, 1991).

Boschen et al (2007) explain that although a systems approach is often advocated within the literature few studies have actually employed this within their research design. However, Yeates et al (2007) did apply a systems approach in a qualitative piece of research where both the injured person and their primary carer were interviewed. They identified that family members used previous knowledge of the injured person as a resource to make sense of what was seen or experienced post injury. This knowledge was contextually bound within the family system and as such family context was a significant feature of the family member's ability to make sense of brain injury and the subsequent life changes that followed. This study illustrates the importance of the exploration of family contexts and the family system in order to understand the family experience of traumatic brain injury.

*Family Centred Care (Subheading)*

The publication "People first: a shared vision and commitment to the transformation of adult social care" (DoH, 2007) describes how services should be personally tailored to meet individual needs. MacKean et al (2005) argue that, in comparison to other fields of nursing, children's services are far closer to this personalisation agenda because of the well established use of

Family Centred Care (FCC). FCC within children's nursing is promoted as the underpinning philosophy of care (DoH, 1991, Audit Comission for England and Wales 1993) and emerged in the care of children through the understanding that the presence of parents was beneficial to the sick child's recovery (Hutchfeild, 1999). FCC helps parents to continue in their established caring role (Brunner and Suddarth, 1989) and later in the child's life, as parental roles change, older children are expected to take more of an active role in their own care (Sheild's et al 2008). FCC accepts that a child's health is interdependent on family members, specifically parents, and this collective effort aims to support attainment of the child's desired health and social outcomes. Similarly in TBI the family is required to care, support and adapt in response to the needs of the injured member. Therefore although FCC is not applied in the same way in the adult setting a holistic approach to care should involve consideration of, and collaboration with, the family.

Definitions of FCC vary greatly (Hutchfield 1999) and they usually refer to care of the child however the definition below illustrates how FCC does not have to be applied to the paediatric setting alone.

*"Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.* (Institute for Family Centered Care, 2008, www.familycenteredcare.org)

FCC is said to consist of nine elements that assist healthcare professionals to work with parents and families to improve the care received by children (Shelton, Jeppson and Johnson, 1987, cited by Johnson, 1990). It would not be appropriate to transfer these principles directly to the care of an adult however Box 2 shows further development of these principles to suggest how FCC may be applied within the context of brain injury. These should be viewed as principles of good practice and could be used as a framework to managing TBI within the context of the whole family.

It is important to acknowledge that not all FCC is implemented well. Darbyshire (1994) and Coyne (1996) for example report that the roles of family members and professionals are not always negotiated or clearly understood. This can lead to poor communication and lack of satisfaction with care. Shields et al (2006) suggest that nurses may be taking parental participation in care for granted and this is causing parents to feel resentment. If FCC were to be adopted in brain injury services careful implementation would be required so that the same problems are not encountered. Finally, although there is a large amount of anecdotal evidence regarding the value of FCC in the care of children, a recent Cochrane review concluded that there was insufficient rigorously conducted research and were unable to measure the efficacy of this approach (Shields et al, 2007). Careful studies of the potential role and effectiveness of FCC in brain injury services is therefore a prerequisite of any change.

**Conclusion**

Applying a family systems approach to understanding family dynamics and the family context may help practitioners to plan more individualised and effective care. Using FCC is one possible framework to develop care delivery. However there is currently little evidence to suggest FCC

within the adult setting will be helpful. Future research is needed that will suggest ways in which the whole-family approach to managing TBI can be achieved. Qualitative research will help in the early stages of understanding family in the context of TBI. Evidence developed in this way may reveal a framework for modelling interventions which are responsive to the needs of the whole family. The efficacy of any such model should then be rigorously evaluated through a quantitative research design. Healthcare services may then know the true value of any such intervention for patients and families affected by TBI.

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**Box 1: Key points of family systems theory**

- A family's structure and organisation are important factors determining the behaviour of family members
- Family functioning cannot be fully understood by simply understanding each of the parts
- The parts of the family are interrelated
- One part of the family cannot be understood in isolation from the rest of the system

(Walker & Akister, 2004, p16 )

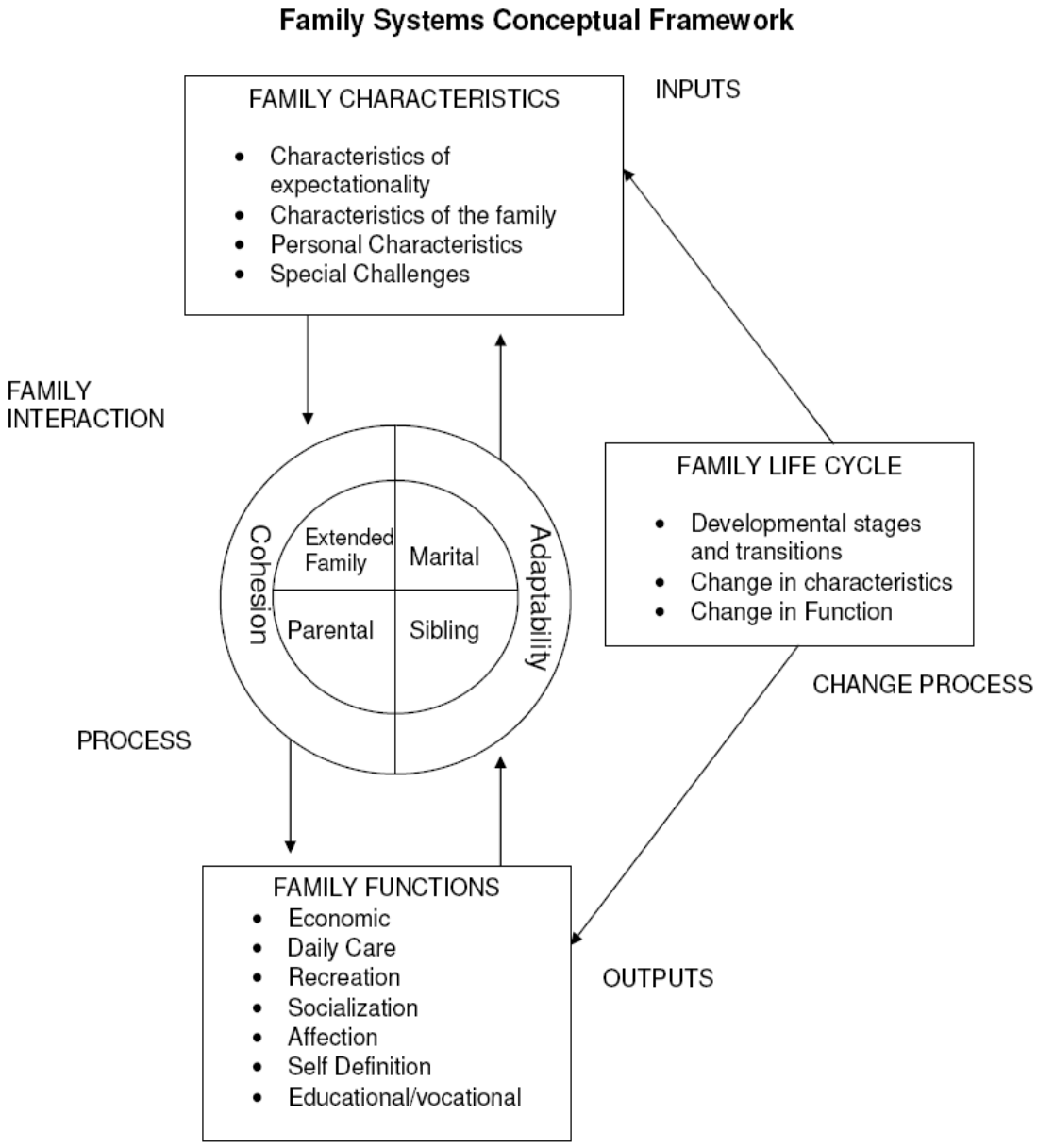
**Box 2: The Nine Elements of Family Centred Care:**

- Recognising the family as a constant in the patient's life, while the service systems and personnel within those systems fluctuate
- Facilitating family-professional collaboration at all levels of health care
- Honouring the racial, ethnic, cultural, and socio-economic diversity of families
- Recognising family strengths and individuality and respecting different methods of coping
- Sharing complete and unbiased information with families on a continuous basis
- Encouraging and facilitating family-to-family support and networking
- Understanding and responding to patient and family needs as part of healthcare practices
- Adopting policies and practices that provide emotional and financial support to meet the needs of families

- Designing health care that is flexible, culturally competent, and responsive to family-identified needs.

(Adapted from Johnson, 1990, p.237, who developed the original work of Shelton, Jeppson and Johnson, 1987)

Fig.1



(Turnball and Turnball, 1991)